NEWBORN SCREENING FOR CRITICAL CONGENITAL HEART DISEASE (CCHD) IN NEVADA

Testimony on behalf of the

March of Dimes

Before the Assembly Health & Human Services Committee

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Presented by:

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My name is Michelle Gorelow. I am the Director of Program Services for the March of Dimes Nevada Chapter. I am here on behalf of approximately 36,000 babies born in Nevada each year and volunteers and staff members of the March of Dimes to ask for your support for a very important issue related to our mission of giving all babies a healthy start in life. The passage of SB 92 would ensure that all babies born would be screened for critical congenital heart disease.

Newborn screening is a public health program designed for early identification of disorders in newborns shortly after birth that may not be evident and can lead to morbidity and mortality. Early detection, diagnosis, and treatment of certain genetic, metabolic, and endocrine disorders, as well as some functional disorders that can lead to a significant reduction of death, disease, and associated disabilities.

Newborn screening programs in the United States began with the work of Dr. Robert Guthrie, a March of Dimes funded researcher who in the 1960s developed a screening test for phenylketonuria, also known as PKU. PKU is a rare condition in which the baby is born without the ability to breakdown certain amino acids. When undetected, it can lead to irreversible intellectual disabilities.

Currently, there are 31 newborn screening conditions included on the Recommended Uniform Screening Panel, which are recommended for inclusion to the Secretary of the U.S. Department of Health and Human Services by the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children. In September 2011, the Secretary added critical congenital heart disease (CCHD) to the panel.

CCHD is a problem with the heart’s structure and/or function that is present at birth and which causes severe, life-threatening symptoms and requires medical intervention within the first few hours, days, or months of life. CCHD can be identified using a non-invasive and painless method called pulse oximetry which measures the percent oxygen saturation of hemoglobin in the arterial
blood through a sensor that is attached to the baby’s finger or foot. Ten states are currently screening for CCHD and six more have passed legislation to do so in the near future.

**Why is CCHD screening important?**

CCHD screening through pulse oximetry is cost effective. It is estimated to cost between $5 and $10.¹ Echocardiograms, can run into the hundreds and thousands of dollars, and are not a cost-effective means to screen all newborns.

Without screening, some newborns with CCHD might be missed, because the signs might not be evident until after the baby has been discharged from the hospital. It is estimated that about 300 infants with an unrecognized CCHD are discharged every year from newborn nurseries in the United States. Newborns with unrecognized CCHD may not survive or may suffer unnecessary related consequences if their condition is not addressed promptly. Passage of Senate Bill 92 would ensure that all babies born in Nevada would be screened for critical congenital heart disease, thus identifying approximately 4 to 5 additional newborns each year of a potentially life threatening condition.

The March of Dimes urges members of the Assembly Health and Human Services Committee to make sure that babies in Nevada are protected by supporting SB92 to ensure screening for critical congenital heart disease.

Thank you for your time and allowing the March of Dimes to testify on SB92.

For more information, please contact Michelle Gorelow at mgorelow@marchofdimes.com or 702-690-0717.

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¹ Center for Disease Control